Report of Services for Mentally Disabled Children

Presented Pursuant To Public Act 93-0599



Illinois Department of Public Aid

Rod R. Blagojevich, Governor Barry S. Maram, Director

December 2003



Illinois Department of Public Aid

201 South Grand Avenue East Springfield, Illinois 62763-0002

Telephone: (217) 782-1200

TTY: (800) 526-5812

December 2003

Governor Blagojevich and Honorable Members of the General Assembly:

I am pleased to present this report in response to Public Act 93-0599 regarding:

- the status of existing services offered under 305 ILCS 5/5-2(7), the home and community-based services (HCBS) waiver for children under age 21 who are medically fragile and technology dependent; and
- the extent to which the existing programs could provide coverage for children
 with mental disabilities who are currently being provided services in an
 institution who could otherwise be served in a less-restrictive, communitybased setting for the same or a lower cost.

This report provides detailed service and expenditure information on:

- Illinois' medically fragile, technology dependent children's home and community-based services waiver and comparable institutional settings;
- state options for receiving federal funds to serve children with disabilities;
- existing state programs that serve children with disabilities; and
- state initiatives to better assess and meet the needs of children with mental disabilities.

The report was prepared in collaboration with the University of Illinois at Chicago Division of Specialized Care for Children and the Illinois Department of Human Services. I will take this opportunity to express my appreciation for their support.

Sincerely,

Barry S. Maram Director

TABLE OF CONTENTS

TABLE OF CONTENTS	i
LIST OF TABLES	ii
INTRODUCTION	1
BACKGROUND	1
Medicaid Home and Community-Based Services Waivers Medicaid TEFRA Option	
STATUS OF SERVICES UNDER 5/5-2(7) OF THE PUBLIC AID CODE	4
Illinois' HCBS Waiver for Medically Fragile, Technology Dependent Children	4
EXISTING OPTIONS FOR INSTITUTIONALIZED CHILDREN WITH MENTAL DISABILITIES	11
Definition of Population and Institutional Settings Other Existing HCBS Programs Other Programs	12
OTHER INITIATIVES IN ILLINOIS	13
Children's Mental Health Act of 2003 - Public Act 93-0495 Disability Database - Public Act 93-0503 Real Choice Systems Change Grant The Autism Project - Public Act 93-0395	14 14
APPENDICES	
Appendix A – Public Act 93-0599	9 14
· ·	2

LIST OF TABLES

Table 1.	HCBS Waivers and TEFRA Comparisons	3
Table 2.	Participants, Capacity and Expenditures by Waiver Year	5
Table 3.	Basic Medicaid Services Provided to MF/TD Waiver Children	6
Table 4.	MF/TD Waiver Services	7
Table 5.	MF/TD Basic Medicaid Services Expenditures By Cost Comparison	
	Group	7
Table 6.	MF/TD Basic Medicaid Services Detailed Expenditures	8
Table 7.	Comparative Costs – Institution to Waiver	9

Report of Services for Mentally Disabled Children Public Act 93-0599

December 2003

INTRODUCTION

Public Act 93-0599 amended the Illinois Public Aid Code to add a new section, 305 ILCS 5/5-2.05. (See Appendix A.) The law gives the Department of Public Aid (DPA) authority to offer home-based and community-based services (HCBS) instead of institutional placement to severely mentally ill or emotionally disturbed children who would otherwise not qualify for medical assistance because their families have too much income.

The law also requires DPA, in conjunction with the Department of Human Services (DHS) and the Division of Specialized Care for Children (DSCC), to report to the Governor and General Assembly regarding the status of services provided under 305 ILCS 5/5-2 (7). The law provides that the report shall also include information regarding the extent to which existing programs could provide community-based services for children with mental disabilities who are currently served in an institution.

This report is presented in response to the latter requirement.

BACKGROUND

Medicaid Home and Community-Based Services Waivers

Medicaid is the federal program authorized under Title XIX of the Social Security Act to reimburse states for providing health benefits to low-income persons. The federal law sets out requirements and limitations that states must follow in operating their programs. Medical assistance provided in Illinois under the Public Aid Code generally qualifies for reimbursement by the federal government under Title XIX at a rate of 50 percent.

Title XIX limits the kinds of services that states may provide. Generally speaking, eligible services must be of a medical or rehabilitative nature. Certain services needed to allow a child with disabilities to remain at home, for example, environmental modification, habilitation services, and respite care, are restricted by Title XIX.

The Secretary of the U.S. Department of Health and Human Services (DHHS) is authorized to waive certain Title XIX requirements to enable states to receive reimbursement for home- and community-based services. Such waivers are generally granted under the authority of Section 1915(c) of the Social Security Act and are referred to as HCBS waivers. Illinois has been granted a total of seven HCBS waivers.

HCBS waivers permit states to provide home- and community-based services other than room and board to individuals who would otherwise require an institutional level of care. Essentially, these waivers allow states to cover a wide range of additional services as long as the services are required to keep a person from being institutionalized.

A state may receive federal Medicaid match for persons enrolled in HCBS waiver programs only if those persons are eligible for Medicaid. Such persons must meet Medicaid's financial limits (income and assets) and nonfinancial eligibility factors (fit into an eligible group: children, parents, seniors, disabled; live in Illinois; be a U.S. citizen or a qualified legal alien, for example). Under HCBS waivers, however, states may choose not to count parents' income and assets when determining whether a child is eligible. Anyone who qualifies for a waiver is also eligible for all other Medicaid services provided by the state. Here in Illinois, the state has chosen to exempt parental income in the HCBS waiver for Medically Fragile, Technology Dependent children but has not chosen to exempt such income in the DHS Division of Rehabilitation Services waiver programs.

The HCBS waivers also allow states flexibility in developing alternatives to placing Medicaid-eligible individuals in hospitals, nursing facilities or intermediate care facilities for persons with mental retardation (ICFs/MR). HCBS waivers allow states flexibility to select a mix of services that best serves the population of individuals covered. HCBS waivers may be limited to persons having a particular disability or who are of a certain age and do not have to operate statewide. The number of participants in an HCBS waiver program may be capped, although once a participant is enrolled, the participant is entitled to all medically necessary services made available to any other participant under that waiver. An individual may only receive services under only one waiver at a time.

The state must assure DHHS that the cost of providing home- or community-based services will not exceed the cost of care for the identical population in an institution. In addition, the state must document that safeguards are in place to protect the health, safety, and welfare of those served.

HCBS waivers are initially approved for a three-year period. They may subsequently be renewed for five-year periods as long as the state satisfies federal reviewers that the waiver is operated within federal guidelines relating to the health, safety, and welfare of the participants, and the total federal spending for participants' support does not exceed the cost of care in an institution. These waiver programs are subjected to much closer federal oversight than a state's base Medicaid program.

Medicaid TEFRA Option

Under Section 143 of the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA), states also have the option of making Medicaid benefits available to certain children with disabilities who would not ordinarily be eligible for Supplemental Security Income (SSI) because of their parent's income or resources. This provision is often called the "Katie Beckett" option. Not counting parental income enables these children to receive

Medicaid services at home or in other community settings. The state must determine that the child needs the level of care provided in an institution, that the child's care can be appropriately provided outside an institution, and that the cost of home or community care is no more than the cost of institutional care. The TEFRA option offers states much of the flexibility of HCBS waivers and is administratively less complex. On the other hand, states may not target specific populations or cap enrollment under the TEFRA option.

Table 1. HCBS Waivers and TEFRA Option Compared

	HCBS Waivers	TEFRA
Family Income	May disregard	May disregard
Disability	Can be limited to certain disabilities	All children who qualify are eligible regardless of physical or mental disability
Age	Up to age 21	Up to age 18
Services	Can receive additional services under the waiver as well as the same services available to Medicaid eligible children.	Same services available to Medicaid eligible children
Limitations	States may limit numbers or geographic location served	Entitlement-offered statewide with no limits on the number served.
Eligibility	 Must require hospital, nursing facility, or ICF/MR institutional level of care. Is appropriate to provide care outside the facility; and The cost of care at home is no more than the cost of institutional care. Note: child residential treatment facilities are not included within the definition of institutions. * 	 Must require the level of care provided in an institution and meet SSI standards for disability. Is appropriate to provide care outside the facility; and The cost of care at home is no more than the cost of institutional care. Note: child residential treatment facilities are not included within the definition of institutions. *
Approval	Waiver application- Must be approved by CMS Central Office	State plan amendment –Must be approved by CMS Regional Office
Administration	Requires extensive administrative oversight, administrative rules, annual reports of cost effectiveness and assurances of health, safety and welfare, periodic renewals and CMS audits	Requires administrative rules including eligibility requirements

^{*} The definition of institutions under Section 1915c includes hospital, nursing facility or ICF/MR.

STATUS OF SERVICES UNDER 5/5-2(7) OF THE PUBLIC AID CODE

Illinois' HCBS Waiver for Medically Fragile, Technology Dependent Children

At 305 ILCS 5/5-2 (7), the Public Aid Code authorizes an HCBS waiver program for children. The law specifically provides that medical assistance shall be available to:

Persons who are under 21 years of age and would qualify as disabled as defined under the Federal Supplemental Security Income Program, provided medical service for such persons would be eligible for Federal Financial Participation, and provided the Illinois Department determines that:

- the person requires a level of care provided by a hospital, skilled nursing facility, or intermediate care facility, as determined by a physician licensed to practice medicine in all its branches;
- it is appropriate to provide such care outside of an institution, as determined by a physician licensed to practice medicine in all its branches;
- c) the estimated amount, which would be expended for care outside the institution, is not greater than the estimated amount, which would be expended in an institution.

Illinois currently has one HCBS program operating under this provision of the Public Aid Code. It is administered by DPA and operated by the University of Illinois at Chicago (UIC) Division of Specialized Care for Children (DSCC). The program serves children younger than age 21 who are medically fragile and technology dependent (MF/TD).

The MF/TD HCBS waiver serves children who would otherwise require institutional care in a hospital or skilled pediatric nursing facility (SNF/Ped). The estimated cost to the state for their in-home care cannot exceed that of the cost of care to the state in the institutional settings. Since the MF/TD waiver is specifically designed for children who are both medically fragile and technology dependent, children who require institutionalization solely because of a severe mental or developmental impairment are unlikely to be eligible to receive services under this waiver.

DPA maintains administrative oversight of the waiver program, and DSCC is responsible for day-to-day operations. Funding for the waiver is appropriated to DPA, and DPA approves the plans of care prior to children receiving such care. DSCC provides case management, processes claims for nursing payments, and monitors the delivery of waiver services.

The waiver is subject to federal approval and renewal every five years by the Centers for Medicare and Medicaid Services (CMS). It was initially approved in 1985 for 50 children and is currently approved through August 31, 2007. DPA received approval from CMS in 2002 to serve up to 450 children to ensure that medically eligible children would receive needed services. CMS approved a gradual increase over the next five years as reflected in Table 2 below.

Children must first meet medical eligibility for the waiver. This is determined through the review and approval of the medical plan of care by a team of DPA physician and nurse consultants. Once medical need is established, the plan and the child's resources are subject to the financial review for cost neutrality described above. Parental income is waived in the financial eligibility determination if the child would otherwise be eligible for Medicaid with parental income excluded. Children enrolled in the waiver are then eligible for all Medicaid services. Approximately one-third of the children in the waiver would not be financially eligible for Medicaid services if Illinois counted their parent's income.

In compliance with Public Act 93-0599, this report includes the following information concerning the MF/TD waiver program:

- 1. The number of persons eligible for waiver services.
- 2. The number of persons who applied for waiver services.
- 3. The number of persons who currently receive these services.
- 4. The nature, scope and cost of waiver services provided.
- 5. The comparative cost of providing those services in a hospital, skilled nursing facility, or intermediate care facility.
- 6. The funding source for the provision of services, including federal financial participation.
- 7. The qualifications, skills, and availability of caregivers for children receiving services.

In this report, waiver year 2002 data has been used unless otherwise specified because waiver year 2003 data is incomplete. Waiver year 2002 covers the period September 1, 2001 to August 31, 2002.

Number Of Persons Eligible For Waiver Services.

The Department attempted but was unable to identify a source that would reflect the universe of children in Illinois with MF/TD needs. However, it appears that the waiver is serving most, if not all, individuals who are eligible and need the service. Waiver capacity has been increased as needed and there are no waiting lists for this program. (See Table 2.)

Table 2. Participants and Capacity by Waiver Year

Year	WY* 1999	WY 2000	WY 2001	WY 2002	WY 2003 (To Date)	WY 2004 (To Date)	WY 2005- 2007
Unduplicated Participants	291	313	350	412	458	456	2007
Capacity	400	350	375	450**	525	600	700

^{*} WY (Waiver Year): September 1 through August 31

^{**} Increased from 400 to 450 via a June 2002 waiver amendment
The waiver renewal in September 2002 increased the waiver capacity for WYs 2003-2007

Number Of Persons Who Applied For Waiver Services.

In WY2002, 168 children applied for the waiver program. A total of 121 entered the waiver and 47 did not. Some of the reasons that the children did not enter the waiver include: used other resources (insurance, trusts), did not meet medical eligibility requirements, died prior to discharge to home, moved out-of-state, chose other placement, or family withdrew. In general, the individual's medical needs must include technology assistance, such as mechanical ventilation, and the condition must be such that medical care needs require hospital or SNF/Ped care, or in other words, continuous, not intermittent, nursing care.

Number Of Persons Who Currently Receive Waiver Services.

As of December 1, 2003, 443 children were receiving services in the MF/TD HCBS waiver.

Nature, Scope, And Cost Of Waiver Services.

Waiver services are services not otherwise covered under the Medicaid program for children. Under federal law, all medically necessary services described in Section 1905(a) of the Social Security Act must be provided to children. This includes a wide range of preventive and therapeutic services.

Nursing services, hospital care, durable medical equipment and supplies, are services most frequently used by children in the MF/TD waiver. These services are regular Medicaid Services and do not require a waiver. (See Table 3.)

Table 3. Basic Medicaid Services Provided to MF/TD Waiver Children Waiver Year 2002 Total Children: 412						
Basic Medicaid Service Unduplicated Total Expenditures Average Participants Per Capita						
Nursing	410	\$35,838,395	\$87,411			
Inpatient Hospital	100	\$ 5,105,918	\$51,059			
Medical Equipment	321	\$ 2,872,422	\$ 8,948			
Medical Supplies	345	\$ 1,887,510	\$ 5,471			

Services available only under the waiver include respite and environmental modifications along with a few other services unique to this waiver population. Of notable interest, waiver service costs are significantly less than Medicaid covered non-waiver service costs. (See Table 4.)

Table 4. MF/TD Waiver Services Waiver Year 2002 Total Children: 412						
Waiver Services Unduplicated Total Average Participants Expenditures Per Capita						
Respite	304	\$1,417,909	\$4,664			
Environmental Modifications	122	\$ 226,759	\$1,859			
Medically Supervised Day Care*	0	0	0			
Special Equipment**	0	0	0			
Placement Counseling***	0	0	0			

^{*} There are currently no licensed medically supervised day care facilities. The Department of Children and Family Services (DCFS) anticipates certification of one provider in calendar year 2004.

Children enrolled under the MF/TD waiver also receive other covered Medicaid services. In Table 5, non-waiver (basic Medicaid) costs of children who would be hospitalized if not for receipt of waiver services are displayed separately from non-waiver costs of children who would otherwise qualify for SNF-Ped services. Table 5 includes breakdowns of unique users, total costs, and the average cost per child of:

- Hospital compared non-waiver services
- SNF/Ped non-waiver services

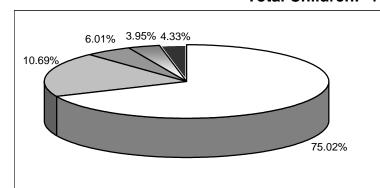
Table 5. MF/TD Basic Medicaid Services Expenditures By Cost Comparison Group Waiver Year 2002 Total Children: 412					
Cost Unduplicated Total Av Comparison Participants Expenditures Per					
Hospital	360	\$43,734,370	\$121,484		
SNF/Ped	52	\$ 4,037,496	\$ 77,644		

Table 6 details the four largest categories of non-waiver (basic Medicaid) services and all other expenditures by cost and percent of total costs for children enrolled in the MF/TD waiver.

^{**} In general, Medicaid covers medical equipment and supplies. This service is included in the waiver for situations where children may need special equipment not otherwise covered.

^{***} Placement maintenance counseling is a unique service that provides short-term, issue-specific family counseling or individual counseling to maintain the child in the home placement. It is rarely used.

Table 6. MF/TD Basic Medicaid Services Detailed Expenditures
Waiver Year 2002
Total Children: 412



75.02% Private Duty Nursing/ Other Nursing

10.69% Inpatient Hospital Services

6.01% Medical Equipment

3.95% Medical Supplies

4.33% Other

Service Breakdown	Total Cost		Percent %
Private Duty Nursing/ Other Nursing & Certified Nurse Aide Services	\$	35,838,395	75.02%
Inpatient Hospital Services	\$	5,105,918	10.69%
Medical Equipment/Prosthetic Devices	\$	2,872,422	6.01%
Medical Supplies	\$	1,887,518	3.95%
All Other Total	\$	2,067,621	4.33%
(Breakdown of All Other) • Physician Services	\$	(500,187)	(1.05%)
 Therapies (Physical, occupational & speech; includes El therapies) 	\$	(437,736)	(.91%)
Outpatient Services	\$	(303,877)	(.64%)
Prescription Drugs	\$	(253,637)	(.53%)
School Health Services (Includes medical services in Individual Education Plan (IEP)	\$	(269,363)	(.56%)
Early Intervention Services (Excludes therapies)	\$	(120,603)	(.25%)
All Other Medical Services (Lab, x-rays, optical, dental, audiology, podiatry, healthy kids services, mental health, transportation, & others)	\$	(183,218)	(.38%)
Total Expenditures	\$	47,771,866	100.00%

Comparative Cost Of Providing Those Services In A Hospital, Skilled Nursing Facility, Or Intermediate Care Facility.

This HCBS waiver's cost comparison is to hospitals and SNF/Peds. SNF/Peds admit young people who are medically fragile and require nursing services in addition to services for their developmental disabilities.

Table 7 displays the estimate of what it would cost the state to serve waiver children in the absence of home-based or community services. The cost comparisons are split into two groups: children who would otherwise require hospitalization and those who would otherwise be served in a SNF/Ped.

Table 7. Per Capita Comparative Costs - Institution to Community Waiver Year 2002

Institutional Level of Care	Average Per Capita Cost Without HCBS	Average Per Capita Cost With HCBS	
Hospital	\$ 124,313	\$ 121,484	
SNF/PED	\$ 80,246	\$ 77,644	

Funding Sources For The Provision Of Services, Including Federal Financial Participation.

Funding for MF/TD waiver services is appropriated to DPA from the General Revenue Fund. Prior to state fiscal year 2004, waiver services were paid from DPA's home health care appropriation. For state fiscal year 2004, DPA received a separate appropriation line of \$51,620,900 for waiver services. The home health care appropriation was reduced accordingly. DSCC has authority to pay home health and nursing agency providers for waiver services out of this DPA appropriation. Other medical services for children enrolled in the waiver are paid by DPA from its appropriations for hospital, physician, home health and other services respectively.

Federal financial participation for this program is generally 50 percent of expenditures for eligible services. This federal reimbursement rate was temporarily increased to 52.95 percent for expenditures made between April 1, 2003 and June 30, 2004. In addition, both DPA's and DSCC's expenses for administering this waiver program are eligible for federal match at a rate of 50 percent.

Qualifications, Skills And Availability Of Caregivers For Children Receiving Services.

Illinois has an enrollment of 239 home health agencies, but only a specialized group of nursing agencies serves the highly technology-dependent pediatric population with shift nursing care. There are 70 providers (69 home health agencies or private duty nursing agencies and one children's community-based health center) enrolled with DPA and approved by DSCC to provide nursing services in the MF/TD HCBS waiver program.

DSCC has specific guidelines and approves providers of private duty nursing services and the children's community-based health center under the waiver. Once approved, and annually thereafter, agencies sign an agreement with DSCC to comply with the requirements of the program. These include qualifications, experience and training for administrative and nursing staff.

Respite care services for children in the MF/TD HCBS waiver are provided by appropriately qualified nurses and home health aides who are licensed and certified in Illinois. The same qualifications apply to private duty nursing services. Nurses and home health aides must be employed by a licensed home health agency or an approved private duty nursing agency, except those providing services in the children's community-based health center who are employed directly by the health center.

Illinois is not immune to the impact of the national shortage of nurses and other health care workers on the availability of caregivers. Agencies providing home-based services must constantly compete with recruitment strategies and wages offered by institutions. So far, by working closely with DSCC and the nursing agencies, DPA has been able to procure and maintain sufficient providers to meet the needs of children in the waiver.

There is no medically supervised day care provider currently certified in Illinois. However, Public Act 93-0402 does amend the Alternative Health Care Delivery Act to include medical day care as a service that may be provided in a children's community-based health center licensed under that act by the Department of Public Health. DCFS certifies medical day care.

Providers of other waiver services, such as environmental modifications, specialized medical equipment and supplies, and placement maintenance counseling, are subject to applicable licensure requirements or qualifications and appropriate experience. Environmental modifications and specialized medical equipment and supplies must be prior approved by DPA. DSCC approves home medical equipment and infusion providers serving children approved for waiver services and requires annual signed agreements. Home medical equipment providers must also be licensed by the Department of Professional Regulation. Placement maintenance counseling is provided by a licensed social worker, licensed clinical psychologist, or an agency certified by DHS Division of Mental Health (DMH) or DCFS to provide clinical or rehabilitation services. To receive payment for covered services, all medical providers must be enrolled with DPA.

EXISTING PROGRAM OPTIONS FOR INSTITUTIONALIZED CHILDREN WITH MENTAL DISABILITIES

Definition of Population and Institutional Settings

For the purposes of this discussion, "mentally disabled children" means children with serious emotional disturbances (SED) or emotional disturbances (ED)¹.

This discussion also requires a clear definition of "institution." Federal law authorizing Medicaid HCBS waivers allows states to cover otherwise nonmatchable services to enable individuals who would otherwise require institutional services to stay at home. Federal regulations further define an institutional setting as a hospital, a nursing facility, or an ICFS/MR. Populations of children in Illinois who require such institutional care are those served in:

- Inpatient psychiatric units,
- · State-operated psychiatric facilities, and
- SNF/Peds.

Psychiatric Hospitalizations

The DHS-Division of Mental Health (DMH) funded psychiatric inpatient hospital services in private hospitals for 569 children under the age of 18 in fiscal year 2003. The average length of stay was 10.97 days for adolescents and 16.42 days for children under the age of 13. All of these individuals received Screening Assessment and Support Services (SASS) services prior to admission. SASS is described in detail below.

In state FY 2002, DPA funded an additional 5,640 children under the age of 19 in psychiatric hospitals with an average length of stay of 9.2 days. So far in FY 2003, 5,281 children with an average length of stay of 9.7 days have been served. This number will probably increase since providers have 12 months from the date of service to bill DPA. This population is subject to the provisions of the newly enacted Children's Mental Health Act described below.

State-Operated Psychiatric Facilities

In state FY03, 137 children were hospitalized in state-operated facilities. The average length of stay was 31.34 days for both children and adolescents.

¹ Children with developmental disabilities as a group were excluded from this analysis primarily because review of services for that population is encompassed by a wide reaching project funded by the Illinois Council on Developmental Disabilities. The first report from the project can be found at www.state.il.us/agency/icdd. Children who are wards of the Department of Children and Family Services are also excluded.

SNF/Ped

There are ten licensed SNF/Peds in Illinois. In September 2003, there were 400 children served in these facilities. SNF/Peds admit young people who are medically fragile and require skilled nursing services in addition to services to address developmental disabilities. These facilities range in size from 42 to 150 beds. Once admitted, residents may stay for as long as the facility continues to meet their needs.

Other Existing HCBS Programs

Illinois currently operates six HCBS waivers in addition to the MF/TD waiver. Three of them are available to children. These are operated by DHS Division of Rehabilitation Services (DRS) and include:

- HCBS for persons with physical disabilities,
- HCBS for persons with HIV/AIDS, and
- HCBS for persons with brain injuries.

About 2,500 children are served under those waivers. Although parents' income is waived when considering a child's eligibility for MF/TD services, according to current program rules, children served under the DHS-DRS HCBS programs must meet financial eligibility for Medicaid including counting parents' income. Children who are not eligible for Medicaid but whose families have no more than \$30,000 in non-exempt family assets are served by DHS-DRS at 100 percent state expense.

Disabilities that do not independently meet the medical criteria for eligibility for the existing HCBS programs include: developmental disabilities (DD), severe mental illness or emotional disturbance and autism. The existing HCBS programs were not designed to cover services for children who are in an institution solely for severe mental disabilities. Supports are provided to these children through other programs offered by DHS. In addition, the Real Choice Systems Change Grant discussed later in this report is supporting review of whether a new Medicaid HCBS waiver should be created to address the needs of children with mental health needs.

DPA has identified one group of children for whom no state program has been identified – whether institutional or community-based. These are children with autism who have normal intelligence. These children may be the most difficult to serve in current programs because they are neither developmentally disabled nor mentally ill.

Other Programs

The DHS-DMH operates the Individual Care Grant (ICG) program that provides financial assistance to parents and other legal guardians of children and adolescents with severe mental illness. The program funds residential placement or specialized, community mental health services.

Any child or adolescent who meets the eligibility criteria is awarded a grant. The grant award is not dependent on family income, and there is no cap on the number of awards. During fiscal year 2003, 444 children and adolescents used an ICG. Residential facilities provide a structured environment 24 hours a day, seven days a week. The average cost per year for treatment in a residential facility is approximately \$80,000. Those receiving services in their community live at home and receive specialized intensive psychiatric care from the local mental health agency. The average per year cost of community services is approximately \$20,000.

The Children's Mental Health Act requires changes in the ICG program as discussed below and it is possible that such changes might lead to expansions of services or coverage for children with mental health needs.

Through its SASS program, DMH finances emergency assessment and crisis intervention to divert children from admission for inpatient psychiatric care. SASS programs are available 24 hours a day, 7 days a week, to deliver screening, crisis intervention and case management to youth at risk for psychiatric hospitalization. Services ensure that children in crisis or in need of mental health services receive the least restrictive, most appropriate level of care with an emphasis on community-based services. If a child needs hospitalization, SASS provides hospitalization services to monitor inpatient care, to advocate for the child, and to ensure continuity of care. SASS providers also actively participate in treatment staffings and discharge planning. Post hospitalization services are provided to stabilize and maintain the child in their home and community. SASS provides post-hospital case management along with comprehensive treatment planning and intensive community-based services such as individual and family counseling, and respite care. Parents or caregivers must be involved with SASS as a partner in this process.

DMH also coordinates a comprehensive array of outpatient mental health services for children and adolescents with serious emotional disturbance or emotional disorders and their families. The mental health needs of children are met within their home, school, and community environments. Children's mental health services are system of care dedicated, consumer-centered, family-focused, community-based, and outcome validated. Mental health treatment services include a range of treatments for mental or emotional disorders in which one or more professionals meet with the client or family in ongoing periodic formal sessions to improve the client's ability to cope with problems in daily living, adaptive functioning and role functioning associated with their emotional, cognitive or behavioral symptoms. Outpatient mental health services promote the recovery process by assisting the child and family with issues of empowerment, self-esteem, social/peer support, and social competency.

OTHER INITIATIVES IN ILLINOIS

Several initiatives that address alternatives to institutional care for children with mental disabilities are currently under development in Illinois.

Children's Mental Health Act of 2003 - PA 93-0495 (Appendix D)

This law directs DPA to require screening and assessment of a child prior to any Medicaid-funded inpatient hospital admission for psychiatric services. The screening and assessment shall include a determination of the appropriateness and availability of outpatient support services for necessary treatment. DPA is currently working in collaboration with DHS and the Department of Children and Family Services to develop a coordinated system of assessment and deflection for all children, including all funded children in need of public funding of such services whether Medicaid or non-Medicaid.

This law directs DPA in collaboration with DHS to secure federal financial participation for the ICG program. This will require modification of the ICG program to meet federal requirements.

Disability Database - PA 93-0503 (Appendix E)

Public Act 93-0503, requires DHS to compile and maintain a cross disability database of Illinois residents with a disability who are potentially in need of services funded by DHS. The database will include individuals with mental illnesses, developmental disabilities, and physical disabilities. Demographic and service need data will also be collected such as information on young adults transitioning from special education programs and children and adults living in existing residential facilities.

Real Choice Systems Change Grant

In October 2003, the DHS-DMH was awarded a Real Choice Systems Change Grant for Community Living for Community-Based Treatment Alternatives for Children. The grant is a consumer-led feasibility study that will seek input from providers, families, and teens to identify barriers and recommend changes to psychiatric residential treatment care facilities (RTCs) for children and adolescents with serious emotional disturbances through the ICG program. In addition, a Medicaid waiver option will be reviewed during this 18-month study. It is noteworthy that RTCs are not considered an institutional level of care under Title XIX.

The Autism Project - PA 93-0395 (Appendix F)

The Autism Project is a systems development initiative designed to enhance early identification and treatment of young children with Autism Spectrum Disorders in Illinois, with an emphasis on raising awareness among practitioners. The project is the result of Public Act 93-0395 and funding is through a DHS \$2.5 million Special Projects Grant that is subject to annual renewal. DHS has designated three pilot sites, one in southern Cook County, one in Springfield, and one in the southern seven counties of Illinois. The pilot sites work with Early Intervention (EI) and local schools to identify, coordinate and enhance services through an experience-based training model. The goal of the project is to offer educational opportunities at all levels of care including physicians, EI specialists, psychologists, teachers, day care providers, parents, respite workers, and speech and language therapists. A web site is being developed.

APPENDIX A - Public Aid Code Section 5/5-2.05

Public Act 93-0599

SB989 Enrolled

LRB093 03231 DRJ 03248 b

AN ACT in relation to public aid.

Be it enacted by the People of the State of Illinois, represented in the General Assembly:

Section 5. The Illinois Public Aid Code is amended by adding Section 5-2.05 as follows:

(305 ILCS 5/5-2.05 new)

Sec. 5-2.05. Disabled children.

- (a) The Department of Public Aid may offer, to children with developmental disabilities and severely mentally ill or emotionally disturbed children who otherwise would not qualify for medical assistance under this Article due to family income, home-based and community-based services instead of institutional placement, as allowed under paragraph 7 of Section 5-2.
- (b) The Department of Public Aid, in conjunction with the Department of Human Services and the Division of Specialized Care for Children, University of Illinois-Chicago, shall also report to the Governor and the General Assembly no later than January 1, 2004 regarding the status of existing services offered under paragraph 7 of Section 5-2. This report shall include, but not be limited to, the following information:
 - (1) The number of persons eligible for these services.
 - (2) The number of persons who applied for these services.
 - (3) The number of persons who currently receive these services.

- (4) The nature, scope, and cost of services provided under paragraph 7 of Section 5-2.
- (5) The comparative cost of providing those services in a hospital, skilled nursing facility, or intermediate care facility.
- (6) The funding sources for the provision of services, including federal financial participation.
- (7) The qualifications, skills, and availability of caregivers for children receiving services.

The report shall also include information regarding the extent to which the existing programs could provide coverage for mentally disabled children who are currently being provided services in an institution who could otherwise be served in a less-restrictive, community-based setting for the same or a lower cost.

Section 99. Effective date. This Act takes effect upon becoming law.

Effective Date: 8/26/2003

APPENDIX B - Public Aid Code Section 5/5-2

- 305 ILCS 5/5-2 (from Ch. 23, par. 5-2)
- Sec. 5-2. Classes of Persons Eligible. Medical assistance under this Article shall be available to any of the following classes of persons in respect to whom a plan for coverage has been submitted to the Governor by the Illinois Department and approved by him:
- 1. Recipients of basic maintenance grants under Articles III and IV.
- 2. Persons otherwise eligible for basic maintenance under Articles III and IV but who fail to qualify thereunder on the basis of need, and who have insufficient income and resources to meet the costs of necessary medical care, including but not limited to the following:
 - (a) All persons otherwise eligible for basic maintenance under Article III but who fail to qualify under that Article on the basis of need and who meet either of the following requirements:
 - (i) their income, as determined by the Illinois

 Department in accordance with any federal requirements, is equal to or less than 70% in fiscal year 2001, equal to or less than 85% in fiscal year 2002 and until a date to be determined by the Department by rule, and equal to or less than 100% beginning on the date determined by the Department by rule, of the nonfarm income official poverty line, as defined by the federal Office of Management and Budget and revised annually in accordance with Section 673(2) of the Omnibus Budget Reconciliation Act of 1981, applicable to families of the same size;
 - (ii) their income, after the deduction of costs incurred for medical care and for other types of remedial care, is equal to or less than 70% in fiscal year 2001, equal to or less than 85% in fiscal year 2002 and until a date to be determined by the Department by rule, and equal to or less than 100% beginning on the date determined by the Department by rule, of the nonfarm income official poverty line, as defined in item (i) of this subparagraph (a).
 - (b) All persons who would be determined eligible for such basic maintenance under Article IV by disregarding the maximum earned income permitted by federal law.
- 3. Persons who would otherwise qualify for Aid to the Medically Indigent under Article VII.
- 4. Persons not eligible under any of the preceding paragraphs who fall sick, are injured, or die, not having sufficient money, property or other resources to meet the costs of necessary medical care or funeral and burial

expenses.

- 5. (a) Women during pregnancy, after the fact of pregnancy has been determined by medical diagnosis, and during the 60-day period beginning on the last day of the pregnancy, together with their infants and children born after September 30, 1983, whose income and resources are insufficient to meet the costs of necessary medical care to the maximum extent possible under Title XIX of the Federal Social Security Act.
 - (b) The Illinois Department and the Governor shall provide a plan for coverage of the persons eligible under paragraph 5(a) by April 1, 1990. Such plan shall provide ambulatory prenatal care to pregnant women during a presumptive eligibility period and establish an income eligibility standard that is equal to 133% of the nonfarm income official poverty line, as defined by the federal Office of Management and Budget and revised annually in accordance with Section 673(2) of the Omnibus Budget Reconciliation Act of 1981, applicable to families of the same size, provided that costs incurred for medical care are not taken into account in determining such income eligibility.
 - demonstration in at least one county that will provide medical assistance to pregnant women, together with their infants and children up to one year of age, where the income eligibility standard is set up to 185% of the nonfarm income official poverty line, as defined by the federal Office of Management and Budget. The Illinois Department shall seek and obtain necessary authorization provided under federal law to implement such a demonstration. Such demonstration may establish resource standards that are not more restrictive than those established under Article IV of this Code.
- 6. Persons under the age of 18 who fail to qualify as dependent under Article IV and who have insufficient income and resources to meet the costs of necessary medical care to the maximum extent permitted under Title XIX of the Federal Social Security Act.
- 7. Persons who are under 21 years of age and would qualify as disabled as defined under the Federal Supplemental Security Income Program, provided medical service for such persons would be eligible for Federal Financial Participation, and provided the Illinois Department determines that:
 - (a) the person requires a level of care provided by a hospital, skilled nursing facility, or intermediate care facility, as determined by a physician licensed to practice medicine in all its branches;
 - (b) it is appropriate to provide such care outside of an institution, as determined by a physician licensed to practice medicine in all its branches;

- (c) the estimated amount which would be expended for care outside the institution is not greater than the estimated amount which would be expended in an institution.
- 8. Persons who become ineligible for basic maintenance assistance under Article IV of this Code in programs administered by the Illinois Department due to employment earnings and persons in assistance units comprised of adults and children who become ineligible for basic maintenance assistance under Article VI of this Code due to employment earnings. The plan for coverage for this class of persons shall:
 - (a) extend the medical assistance coverage for up to12 months following termination of basic maintenance assistance; and
 - (b) offer persons who have initially received 6 months of the coverage provided in paragraph (a) above, the option of receiving an additional 6 months of coverage, subject to the following:
 - (i) such coverage shall be pursuant to provisions of the federal Social Security Act;
 - (ii) such coverage shall include all services covered while the person was eligible for basic maintenance assistance;

 - (iv) such coverage shall be suspended in the event of a person's failure without good cause to file in a timely fashion reports required for this coverage under the Social Security Act and coverage shall be reinstated upon the filing of such reports if the person remains otherwise eligible.
- 9. Persons with acquired immunodeficiency syndrome (AIDS) or with AIDS-related conditions with respect to whom there has been a determination that but for home or community-based services such individuals would require the level of care provided in an inpatient hospital, skilled nursing facility or intermediate care facility the cost of which is reimbursed under this Article. Assistance shall be provided to such persons to the maximum extent permitted under Title XIX of the Federal Social Security Act.
- 10. Participants in the long-term care insurance partnership program established under the Partnership for Long-Term Care Act who meet the qualifications for protection of resources described in Section 25 of that Act.
- 11. Persons with disabilities who are employed and eligible for Medicaid, pursuant to Section 1902(a)(10)(A)(ii)(xv) of the Social Security Act, as provided by the Illinois

Department by rule.

- 12. Subject to federal approval, persons who are eligible for medical assistance coverage under applicable provisions of the federal Social Security Act and the federal Breast and Cervical Cancer Prevention and Treatment Act of 2000. Those eligible persons are defined to include, but not be limited to, the following persons:
 - (1) persons who have been screened for breast or cervical cancer under the U.S. Centers for Disease Control and Prevention Breast and Cervical Cancer Program established under Title XV of the federal Public Health Services Act in accordance with the requirements of Section 1504 of that Act as administered by the Illinois Department of Public Health; and
 - (2) persons whose screenings under the above program were funded in whole or in part by funds appropriated to the Illinois Department of Public Health for breast or cervical cancer screening.

"Medical assistance" under this paragraph 12 shall be identical to the benefits provided under the State's approved plan under Title XIX of the Social Security Act. The Department must request federal approval of the coverage under this paragraph 12 within 30 days after the effective date of this amendatory Act of the 92nd General Assembly.

The Illinois Department and the Governor shall provide a plan for coverage of the persons eligible under paragraph 7 as soon as possible after July 1, 1984.

The eligibility of any such person for medical assistance under this Article is not affected by the payment of any grant under the Senior Citizens and Disabled Persons Property Tax Relief and Pharmaceutical Assistance Act or any distributions or items of income described under subparagraph (X) of paragraph (2) of subsection (a) of Section 203 of the Illinois Income Tax Act. The Department shall by rule establish the amounts of assets to be disregarded in determining eligibility for medical assistance, which shall at a minimum equal the amounts to be disregarded under the Federal Supplemental Security Income Program. The amount of assets of a single person to be disregarded shall not be less than \$2,000, and the amount of assets of a married couple to be disregarded shall not be less than \$3,000.

To the extent permitted under federal law, any person found guilty of a second violation of Article VIIIA shall be ineligible for medical assistance under this Article, as provided in Section 8A-8.

The eligibility of any person for medical assistance under this Article shall not be affected by the receipt by the person of donations or benefits from fundraisers held for the person in cases of serious illness, as long as neither the person nor members of the person's family have actual control over the donations or benefits or the disbursement of the donations or benefits.

(Source: P.A. 92-16, eff. 6-28-01; 92-47, eff. 7-3-01; 92-597, eff. 6-28-02; 93-20, eff. 6-20-03.)

APPENDIX C – Illinois Medicaid Services

Table V

Illinois Medical Assistance

Mandatory/Optional Services

FEDERALLY REQUIRED MEDICAL ASSISTANCE SERVICES PROVIDED ILLINOIS

Inpatient hospital care (other than those provided in an institution for mental diseases)

Outpatient hospital care

Ambulatory Services provided by rural health clinics and federally qualified health centers

Other laboratory and x-ray services

Nursing facility and home health services for individuals 21 years of age and older

Early and periodic screening, diagnosis and treatment for individuals under 21 years of age

Family planning services and supplies

Physician services

Nurse-midwife services

Nurse Practitioner (pediatric and family only)

Home Health

- -Nursing Services
- -Home Health Aide
- -Medical supplies, equipment and appliances
- -Physical, occupational and speech therapies; audiology services

Ambulatory services to presumptively-eligible pregnant women

Pregnancy-related services and services for other conditions that might complicate pregnancy

Emergency hospital services to aliens

Medical and Surgical services performed by a dentist

OPTIONAL SERVICES PROVIDED IN ILLINOIS

Podiatric services

Optometric services

Chiropractic services

Other practitioner services

Speech, hearing and language therapy services

Eyeglasses

Screening services

Dental services

-Dentures

Clinic services (Medicaid clinic option)

Physical therapy services

Occupational therapy services

Inpatient psychiatric services for individuals

under 21 years of age

Intermediate care facility services for the mentally

retarded (ICF, MR)

Prosthetic devices including durable medical

equipment and supplies

Diagnostic services including durable medical

equipment and supplies

Preventive services including durable medical

equipment and supplies

Care of individuals 65 years of age or older in institutions of mental disease

-Inpatient hospital services

-Nursing facility services

Home and community based services through federal waivers Services provided through a health maintenance organization

or a prepaid health plan

Special tuberculosis-related services

Rehabilitative services (Medicaid rehabilitation option)

Christian Science sanatoria and nursing services

Nurse anesthesia services

Hospice Care services

Transplants

Transportation

Case management services (targeted case management)

Nursing facility services for individuals under 21

vears of age

Program of All-Inclusive Care of the Elderly (PACE)

Emergency hospital services

Prescribed drugs

APPENDIX D - Children's Mental Health Act

Public Act 93-0495

SB1951 Enrolled

LRB093 08901 RCE 09133 b

AN ACT in relation to children.

WHEREAS, Untreated mental health problems in children have serious fiscal consequences for the State because they affect children's ability to learn and increase their propensity for violence, alcohol and substance abuse, and other delinquent behaviors that are extremely costly to treat; and

WHEREAS, One in 10 children in Illinois suffers from a mental illness severe enough to cause some level of impairment; yet, in any given year only about 20% of these children receive mental health services; and

WHEREAS, Many mental health problems are largely preventable or can be minimized with promotion and early intervention services that have been shown to be effective and that reduce the need for more costly interventions; and

WHEREAS, Children's social development and emotional development are essential underpinnings to school readiness and academic success; and

WHEREAS, A comprehensive, coordinated children's mental health system can help maximize resources and minimize duplication of services; and

WHEREAS, The Illinois Children's Mental Health Task Force engaged a broad, multi-disciplinary group that reached consensus on recommendations that serve as the basis for the provisions of this Act; therefore

Be it enacted by the People of the State of Illinois, represented in the General Assembly:

Section 1. Short title. This Act may be cited as the Children's Mental Health Act of 2003.

Section 5. Children's Mental Health Plan.

- (a) The State of Illinois shall develop a Children's Mental Health Plan containing short-term and long-term recommendations to provide comprehensive, coordinated mental health prevention, early intervention, and treatment services for children from birth through age 18. This Plan shall include but not be limited to:
 - (1) Coordinated provider services and interagency referral networks for children from birth through age 18 to maximize resources and minimize duplication of services.
 - (2) Guidelines for incorporating social and emotional development into school learning standards and educational programs, pursuant to Section 15 of this Act.
 - (3) Protocols for implementing screening and assessment of children prior to any admission to an inpatient hospital for psychiatric services, pursuant to subsection (a) of Section 5-5.23 of the Illinois Public Aid Code.
 - (4) Recommendations regarding a State budget for children's mental health prevention, early intervention, and treatment across all State agencies.
 - (5) Recommendations for State and local mechanisms for integrating federal, State, and local funding sources for children's mental health.
 - (6) Recommendations for building a qualified and adequately trained workforce prepared to provide mental health services for children from birth through age 18 and their families.
 - (7) Recommendations for facilitating research on best practices and model programs, and dissemination of

this information to Illinois policymakers, practitioners, and the general public through training, technical assistance, and educational materials.

- (8) Recommendations for a comprehensive, multi-faceted public awareness campaign to reduce the stigma of mental illness and educate families, the general public, and other key audiences about the benefits of children's social and emotional development, and how to access services.
- (9) Recommendations for creating a quality-driven children's mental health system with shared accountability among key State agencies and programs that conducts ongoing needs assessments, uses outcome indicators and benchmarks to measure progress, and implements quality data tracking and reporting systems.
- (b) The Children's Mental Health Partnership (hereafter referred to as "the Partnership") is created. The Partnership shall have the responsibility of developing and monitoring the implementation of the Children's Mental Health Plan as approved by the Governor. The Children's Mental Health Partnership shall be comprised of: the Secretary of Human Services or his or her designee; the State Superintendent of Education or his or her designee; the directors of the departments of Children and Family Services, Public Aid, Public Health, and Corrections, or their designees; the head of the Illinois Violence Prevention Authority, or his or her designee; the Attorney General or his or her designee; up to 25 representatives of community mental health authorities and statewide mental health, children and family advocacy, early childhood, education, health, substance abuse, violence prevention, and juvenile justice organizations or associations, to be appointed by the Governor; and 2 members of each caucus of the House of Representatives and Senate appointed by the Speaker of the House of Representatives and the President of the Senate, respectively. The Governor shall appoint the Partnership Chair and shall designate a Governor's staff liaison to work with the Partnership.

(c) The Partnership shall submit a Preliminary Plan to the Governor on September 30, 2004 and shall submit the Final Plan on June 30, 2005. Thereafter, on September 30 of each year, the Partnership shall submit an annual report to the Governor on the progress of Plan implementation and recommendations for revisions in the Plan. The Final Plan and annual reports submitted in subsequent years shall include estimates of savings achieved in prior fiscal years under subsection (a) of Section 5-5.23 of the Illinois Public Aid Code and federal financial participation received under subsection (b) of Section 5-5.23 of that Code. The Department of Public Aid shall provide technical assistance in developing these estimates and reports.

Section 10. Office of Mental Health services. The Office of Mental Health within the Department of Human Services shall allow grant and purchase-of-service moneys to be used for services for children from birth through age 18.

Section 15. Mental health and schools.

- (a) The Illinois State Board of Education shall develop and implement a plan to incorporate social and emotional development standards as part of the Illinois Learning Standards for the purpose of enhancing and measuring children's school readiness and ability to achieve academic success. The plan shall be submitted to the Governor, the General Assembly, and the Partnership by December 31, 2004.
- (b) Every Illinois school district shall develop a policy for incorporating social and emotional development into the district's educational program. The policy shall address teaching and assessing social and emotional skills and protocols for responding to children with social, emotional, or mental health problems, or a combination of such problems, that impact learning ability. Each district must submit this policy to the Illinois State Board of Education by August 31, 2004.

Section 95. The Illinois Public Aid Code is amended by adding Section 5-5.23 as follows:

(305 ILCS 5/5-5.23 new)

Sec. 5-5.23. Children's mental health services.

- (a) The Department of Public Aid, by rule, shall require the screening and assessment of a child prior to any Medicaid-funded admission to an inpatient hospital for psychiatric services to be funded by Medicaid. The screening and assessment shall include a determination of the appropriateness and availability of out-patient support services for necessary treatment. The Department, by rule, shall establish methods and standards of payment for the screening, assessment, and necessary alternative support services.
- (b) The Department of Public Aid, to the extent allowable under federal law, shall secure federal financial participation for Individual Care Grant expenditures made by the Department of Human Services for the Medicaid optional service authorized under Section 1905(h) of the federal Social Security Act, pursuant to the provisions of Section 7.1 of the Mental Health and Developmental Disabilities Administrative Act.
- (c) The Department of Public Aid shall work jointly with the Department of Human Services to implement subsections (a) and (b).

Section 99. Effective date. This Act takes effect upon becoming law.

Effective Date: 8/8/2003

APPENDIX E – Disability Database

Public Act 93-0503

SB252 Enrolled

LRB093 09548 BDD 09785 b

AN ACT concerning the Department of Human Services.

Be it enacted by the People of the State of Illinois, represented in the General Assembly:

Section 5. The Department of Human Services Act is amended by adding Section 10-26 as follows:

(20 ILCS 1305/10-26 new)

Sec. 10-26. Disability database.

(a) The Department of Human Services shall compile and maintain a cross-disability database of Illinois residents with a disability who are potentially in need of disability services funded by the Department. The database shall consist of individuals with mental illness, physical disabilities, and developmental disabilities, and shall include, but not be limited to, individuals transitioning from special education to adulthood, individuals in State-operated facilities, individuals in private nursing and residential facilities, and individuals in community integrated living arrangements. Within 30 days after the effective date of this amendatory Act of the 93rd General Assembly, the Secretary of Human Services shall seek input from advisory bodies to the Department, including advisory councils and committees working with the Department in the areas of mental illness, physical disabilities, and developmental disabilities. The database shall be operational by July 1, 2004. The information collected and maintained for the disability database shall include, but is not limited to, the following: (i) the types of services of which the individual is potentially in need; (ii) demographic and identifying

information about the individual; (iii) factors indicating need, including diagnoses, assessment information, age of primary caregivers, and current living situation; (iv) if applicable, the date information about the individual is submitted for inclusion in the database and the types of services sought by the individual; and (v) the representative district in which the individual resides. In collecting and maintaining information under this Section, the Department shall give consideration to cost-effective appropriate services for individuals.

- (b) This amendatory Act of the 93rd General Assembly does not create any new entitlement to a service, program, or benefit, but shall not affect any entitlement to a service, program, or benefit created by any other law. Except for a service, program, or benefit that is an entitlement, a service, program, or benefit provided as a result of the collection and maintenance of the disability database shall be subject to appropriations made by the General Assembly.
- (c) The Department, consistent with applicable federal and State law, shall make general information from the disability database available to the public such as: (i) the number of individuals potentially in need of each type of service, program, or benefit and (ii) the general characteristics of those individuals. The Department shall protect the confidentiality of each individual in the database when releasing database information by not disclosing any personally identifying information.

Section 99. Effective Date. This Act takes effect upon becoming law.

Effective Date: 8/11/2003

APPENDIX F – Autism Diagnosis Education Program

Public Act 93-0395

HB1809 Enrolled

LRB093 04822 DRJ 04878 b

AN ACT in relation to health.

Be it enacted by the People of the State of Illinois, represented in the General Assembly:

Section 5. The Mental Health and Developmental Disabilities Administrative Act is amended by adding Section 57.5 as follows:

(20 ILCS 1705/57.5 new)

Sec. 57.5. Autism diagnosis education program.

- (a) Subject to appropriations, the Department shall contract to establish an autism diagnosis education program for young children. The Department shall establish the program at 3 different sites in the State. The program shall have the following goals:
 - (1) Providing, to medical professionals and others statewide, a systems development initiative that promotes best practice standards for the diagnosis and treatment planning for young children who have autism spectrum disorders, for the purpose of helping existing systems of care to build solid circles of expertise within their ranks.
 - (2) Educating medical practitioners, school personnel, day care providers, parents, and community service providers (including, but not limited to, early intervention and developmental disabilities providers) throughout the State on appropriate diagnosis and treatment of autism.
 - (3) Supporting systems of care for young children with autism spectrum disorders.

(4) Working together with universities and developmental disabilities providers to identify unmet needs and resources.

(5) Encouraging and supporting research on optional services for young children with autism spectrum disorders.

(b) Before January 1, 2006, the Department shall report to the Governor and the General Assembly concerning the progress of the autism diagnosis education program established under this Section.

Section 99. Effective date. This Act takes effect upon becoming law.

Effective Date: 07/29/03

GLOSSARY

CMS Centers for Medicare and Medicaid Services

DCFS Department of Children and Family Services

DD Developmental Disability

DHHS Department of Health and Human Services

DHS Department of Human Services

DMH Division of Mental Health

DPA Department of Public Aid

DRS Division of Rehabilitation Services with DHS

DSCC Division of Specialized Care for Children

ED Emotional Disturbance

El Early Intervention

FY Fiscal Year

GRF General Revenue Fund

HCBS Home and Community-Based Services

ICF, MR Intermediate Care Facilities for persons with Mental Retardation

ICG Individual Care Grant

IEP Individual Education Plan

ILCS Illinois Complied Statutes

MF/TD Medically Fragile, Technology Dependent

MH Mental Health

MIS Medicaid Information System

PA Public Act

RTC Residential Treatment Center

SASS Screening Assessment and Support Services

SED Serious Emotional Disturbances

SNF/Ped Skilled Nursing Facility for Pediatrics

SSA Social Security Administration

TEFRA Tax Equity and Financial Responsibility Act

UIC University of Illinois-Chicago

WY Waiver Year